



Mental Health and Disability Services Redesign 2011

Children's Disability Services Workgroup Minutes

August 30, 2011

10:00 am to 3:15 pm

Polk County River Place

2309 Euclid Avenue, Des Moines, IA 50310

MINUTES

Attendance

Workgroup Members: Jennifer Vermeer, Mark Peltan, Gail Barber, Nicole Beaman, Paula Connolly, Jim Ernst, Jerry Foxhoven, Jason Haglund, Jan Heikes, Janice Lane, Marilyn Lantz, Samantha Murphy, Wendy Rickman, Rhonda Shouse, Jason Smith, David Stout, Debra Waldron

Legislative Representation: None

Facilitator: Kappy Madenwald, Technical Assistance Collaborative (TAC)

DHS Staff: Joanna Schroeder, Laura Larkin, Carmen Davenport, Don Gookin

Other Attendees:

Sara Lupress	Polk County
Joan Discher	Magellan
Kermit Dahler	Jackson Recovery Centers
Lisa Jackson	Parent
Mary O'Brien	Visiting Nurses Services of Iowa
Anna Conradt	Parent
Brad Trow	Iowa House Republican Staff
David Adelman	Cornerstone Government Affairs
Deb Dixon	Department of Inspections & Appeals
Nicole Rand	Exceptional Persons Inc.
Kristie Oliver	Coalition for Family & Children's Services
Shannon Strickler	Iowa Hospital Association
Lyle Krewson	Lutheran Services of Iowa & NASW

Agenda

Agenda Topics:

- Review of best practice information on programs for Transition-Age children/young adults
- Review of data of children currently placed Out Of State (OOS)
- Review of multi-year residential admission trending (both in and out of state)
- Overview of two Systems of Care programs in Iowa
- Outlining a framework for bringing kids home
- Next Steps
- Meeting Summary
- Public Comment

Review of best practice information on programs for Transition-Age children/young adults (see handouts for more information)

Kappy Madenwald began the discussion by asking about how Iowa is using Chafee funds—Federal funds that are largely untapped by states and are intended to serve young people exiting the foster care system. They are being used by Child Welfare for housing subsidies and other services. Kappy has found that the funds are most easily used for the teens and young adults who are fairly stable and already likely to live independently and succeed at higher education. A program in Franklin County, Ohio braids Chafee funds with Medicaid to provide a full array of services and supports for youth transitioning who have had mental health system services and need treatment support to finish their education and maintain stable housing.

Kappy then described the Casey Family Program, “It’s My Life.” The common theme or thread through the program is the rich service array needed for successful transition to young adulthood- employment, basic life skills training (banking, signing a lease, living independently), housing, and socialization. Key points in the discussion included:

- A sizeable number of youth, if they have a successful transition (as many as 1/3), will not need adult mental health services.
- Need to pay attention to vocational skills and employment as many of the youth will need guidance in these areas. Not finishing high school, underemployment and unstable housing put young adults at risk.
- For youth that need adult mental health services, traditional adult treatments are not particularly welcoming particularly for youth who are at greater risk for non-adherence to treatment.
- An important element of successful transition programs is to involve the youth and allow them to make their own choices.
- Young adult mental health services need to be ‘engagement-level services’ vs. action-oriented services. For some young adults who have not had choices about treatment, placement and medications, there is mistrust.
- Newer studies show that the adolescent brain is not fully mature until age 25—impacting judgment.

- In general, staff trained to work with adults are not as effective with young adults. It is easier for youth-trained staff to work with young adults because of their experience working with families and with multiple systems.
- Need to take a systemic approach to transition services with attention to vocation, continuing education, housing, community connectedness, etc.

DHS has partnerships with other systems with areas of brilliance and areas of struggle. There is need to talk more with youth about accountability in successful transition, but youth often do not engage in the conversation based on how DHS presents the information to the youth. A program called, ELEVATE, comprised of youth who have transitioned from the Child Welfare system, has made great strides in Iowa in providing peer to peer mentoring for other youth still in the Child Welfare system.

Jennifer stressed the need to get out of the pattern of using silos for youth across disabilities. Next steps would be to build competencies and to build mental health and intellectual disability services as a system. Youth with a dual diagnosis of mental and intellectual disability have poor transition services.

There was discussion about the service mix for persons ages 18-21, a span of years described by one member as a “no-man’s land.” There appears to be a need for clarity on whether 18-21 year olds can receive services through the youth system, the adult system or both. Iowa Medicaid allows funding through age 21. Habilitation services are available to youth with a mental health diagnosis, but youth with an ID diagnosis often do not qualify for Habilitation since Habilitation services is based on diagnosis and progress. Title V and EPSDT covers youth from 0 up to 21, and provides some safety net for youth with disabilities, and there is funding under Title V. Iowa counties do not fund mental health services for youth.

Service sets for youth between the ages of 18-21 need to look different. Traditional service sets creates barriers to serving real people when the youth do not fit into one of the service sets, such as MI, CMI, ID, or DD. Kappy referenced the Rosie D case in Massachusetts that eventually lead the state to expand the service array with a focus on person-centered care for youth through age 20 and shift the responsibility for serving this age group primarily to the children’s system.

Wraparound Milwaukee Discussion Led by Kappy Madenwald

- Initial focus of project was on hard-core delinquents, with the majority of them in the community vs. residential settings.
- This project started small with a narrow population, but they have built capacity to expand the populations they serve. Project is now focusing on pre-juvenile justice and Child Protection youth and has just started a transition-age youth program.
- Capitated rates for this project were discussed. It was mentioned that the rates are fairly comparable to residential per diems. (Wraparound Milwaukee’s capitated rate is about \$3,700/month.) A member noted that if it costs \$3,700 to serve a child in residential treatment vs. in the community, there is no comparison when it comes to quality of life.

Iowa Medicaid and Child Welfare Reviewed by Jennifer Vermeer:

- Trend to in and out of state PMIC placements – an increasing trend for instate PMIC placements.
- Percentage of out of state placements — slight increase in out of state placements.
- The average cost of services for Iowa Medicaid and Child Welfare has increased since 2007 and the costs per child were higher for Iowa Medicaid than for Child Welfare.
- Gender profiling shows that more males being placed out of state than females.
- Earliest service in the past 5 years — only 2% of the youth were with their family prior to an out of state placement.
- Placement prior to out of state placement could include psychiatric hospitalizations, foster group care, PMIC, or family foster care.
- 75% of children went to an out-of-state facility directly from an inpatient psychiatric hospital. There was some thought that some may have been admitted due to a placement disruption. This will be a key point of intercept for diversion.
- Skilled nursing facilities (SNF) are used for youth with high medical needs. Iowa does not have SNF for youth; this may be a licensing issue. This is a very costly group.

It was suggested by a workgroup member to obtain more data/information on the number of youth broken out by disability (MI or ID) as a way to better understand the service needs and costs for the majority of the youth placed out of state who are not receiving specialized medical services.

Kappy asked if an in state cohort group could be identified? Are there “like” children already being successfully served in the community in Iowa? The discussion then focused on:

- DHS makes the decision to place a youth out of state through an Exception to Policy (ETP).
 - Iowa does not move a Child Welfare youth to an out of state placement if they could be served in Iowa; the youth would be moved to a shelter to wait for an in state bed.
 - For PMICs, Iowa does send youth out of state when the Iowa PMICs have waiting lists.
- Difficulties in defining what is clinical necessity, level of care, a bed, or an outcome.
- Highly intensive behaviors, such as physical aggression and self injurious behaviors, are the greatest need when an out of state placement is needed.
- The Iowa Medicaid reimbursement rate was questioned.

With many youth having multiple out of home placements prior to an out of state placement, Kappy led the discussion on the use of diffusion techniques.

- How the use of a mobile crisis team could be used to provide support and coaching in the home or facility.
- The need for treaters to effectively engage youth and to get away from coercive strategies or power struggles with youth that often lead to treatment/placement

disruption. The focus would be on using person-centered and stage-based interventions in programming and in maintaining safety in the milieu.

Debra Waldron, Community Circle of Care, Presentation:

- Shared how the Maternal Child Health Bureau is looking to focus on older youth needing transition services. This bureau originally was looking at the ISOSCELES project and the areas of focus such as family support, clinical services, linkages to health homes, etc. to lead the way to change systemically. They hope to have this implemented by February 2012.
- Spoke about the use of an Iowa screener, which is funded through the Maternal Child Health Bureau and other funding sources. There are specific mental health questions they ask and collect data on; this information could be available in about a month. Will share the data when available.
- Community Circle of Care (CCOC) in a 10-county area in Northeast Iowa. She provided historical information on how it was developed and how it partners with state agencies, such as CDD, DHS, Child Health Specialty Clinics/UIHC, and IDPH. CCOC was created in Iowa and is specific to Iowa; it is funded by federal, state, local, and community monies. Key components to CCOC:
 - Built on the need to acknowledge family values, wrapping the team around the family, strong collaboration with the service entities and the family, and outcome based and data driven.
 - Use of family team meetings to identify strengths, build community support, identify natural supports, and health needs. The family team meetings can be facilitated by family navigators, if needed.
 - Use life domains, which are all the areas that are recognized as part of an individual's health. Health is not the absence of disease, but a holistic approach to being healthy in each life domain.
 - Partner with 25 entities in NE Iowa to provide what the youth and the family needs, such as skill development, making needed connections, preventing them from leaving the community, etc. All partner agencies need to endorse the values of the family and what the youth/family needs. For CCOC, the youth/family has 'the voice and the choice.'
- Identifying the need for medical assessments. Only 1/3 has needed medical assessments.
- 97% of the youth have remained in their family home with CCOC involvement.
- Strong cultural competency component to CCOC; they have one staff who gets the community involved. This staff person has a strong background in education and does well in engaging others.
- Psych Iowa grew out of the fact that Iowa only has 28 child psychiatrists. This is a strong reason why Health Homes or Primary Care Physicians (PCPs) need to develop mental health competencies. Jack Swanson, MD/Ames developed a toolkit for PCPs to embed mental health competencies into their other skills. This service provides direct psychiatric consult via telephone to PCPs. There is mental health training for PCPs via webinars and face to face; this training also emphasizes the care coordination needs for families.
- List of initiatives, with one being the development of a state of Iowa resource team. They have 15 agencies interested in developing a System of Care.

- Providing technical assistance to Scott County area who wants to build a model.
- Linn County has tried to model a program after CCOC; they are working with Magellan on providing support to develop more services and pay for the services.

Dave Stout, Central Iowa Systems of Care, Presentation:

- Started in October 2009 as a result a RFP awarded through DHS.
- They partner with DHS, Juvenile Court, and Visiting Nurses Services. They have a Memorandum of Agreement (MOA) with Youth Emergency Shelter Services (YESS) for respite and emergency services. The Child Guidance Center provides back-up psychiatric services.
- They interviewed approximately 15 agencies prior to the RFP. Now there are 43 different agencies that are part of the stakeholders, which are evolving into subgroups, such as Parents Support & Engagement and a group to look at evidenced based practices.
- Parents are included in the stakeholder level, and are part of the navigation process.
- Target population was youth with a Serious Emotional Disorder (SED).
- The Care Coordinator assigned to the youth and family plays a key role in:
 - Engaging partners and identifying what services are needed.
 - Keeping the youth and the family engaged and linked to the system of care.
 - Identifies large system issues and barriers to families.
- Referrals come from a variety of sources, with the most referrals coming from Juvenile Court, PMICs/Group Care, and therapists.
- Have had two trainings: Mental Health First Aid and How To Get the Best From Community Providers.
- They had 51 discharges as of 06/30/11, with the majority of the youth being discharged and placed at home with mental health services in place.
- Funding the program is challenging since funding was cut by the Legislature.
- Overall, they have prevented out of home placements or diverted them from CINA/delinquency.
- Have a waiting list of 30 youth. The waiting list moves slowly; the average wait time is four months.

Outlining a framework for bringing youth home

This conversation began by considering the five goals from the Olmstead Plan for Mental Health and Disability Services: State Plan Framework. Workgroup members were asked: “If the plan for redesigning the children’s mental health system is successful, what will children and families say about it?”¹

- Goal I: Welcoming Communities that promote the full participation of Iowans with mental illness or disabilities.

¹ Though parents are represented on the Children’s Workgroup, the goal of this exercise was not to speak “for” parents and children. The resulting “working list” of outcomes is neither complete nor final. It simply serves as a reminder to the workgroup of the kind of outcomes that matter to children and families.

- Youths' Perspective
 - I am not broken and recovery is possible.
 - I am safe.
 - I have friends.
 - I can come back (to services) when I need to.
 - I know where to go and what to do when I need help.
 - I have people who understand me.
 - They don't kick me out when I have a bad day.
 - I don't have to be cured, I can be proud.
 - People are willing to accept my disability.
 - I have supports to be successful at a job.
 - I know where to enter the system and access it.
- Parents' Perspective
 - I am not alone.
 - I feel supported rather than blamed.
 - My community is accessible.
- Goal II: Increase access to information, services, and supports that individuals need to optimally live, learn, work, and recreate in communities of their choice.
 - Youths' Perspective
 - I know that the system is working for me.
 - There are the right kinds of services at the right time to help me.
 - I can access information that is easier to find.
 - Technology is working for me to access the services I need.
 - I don't have to go to the hospital/court to get help.
 - People listen to me and I get the services I need vs. the services that are available.
 - Parents' Perspective
 - I can go anywhere and get information, and there is no wrong door.
 - I can identify someone who is knowledgeable.
 - The resources are in formats and language that makes sense to me.
 - I don't have to hear about services from other parents. I can hear about services from the system.
- Goal III: A full array of community based services and supports that are practically available to all Iowans.
 - Youths' Perspective
 - I can access services with ease. I don't have to drive far and can use telemedicine.
 - I have services in my community/home.
 - I don't have to miss time away from home or friends to get services.
 - I have a school that is part of my team.
 - If there is an emergency, someone is there.
 - I can access services/have medications adjusted 24/7.
 - If I need medicine changes, I know that I can access services.

- I know that my service providers are competent and talk to each other.
 - I know the services I need are affordable.
 - I help identify and design the array of services.
 - The services are respectful of my culture, values, priorities and family.
 - I know that I will have a safe place to live.
 - Parents' Perspective
 - There is evidence the system is working.
- Goal IV: High quality services and supports.
 - Youths' Perspective
 - Direct care workers are well-trained.
 - I am part of a community; I belong and am not living a parallel life—I have wholeness of life.
 - I know the services are making a difference.
 - This service that I being provided to our family has proven to be effective.
 - The services that I need are available to me no matter where I live in the state.
 - The supports and services are simple and easy to access/understand.
 - Parents' Perspective
 - I am seen as an expert re: my child. This validates that my being there is just as important as a professional's.
 - I can make choices, give input and set priorities for my family.
 - I am encouraged to give feedback.
 - I feel better and have a hopeful future.
 - The workers that come to my home are consistent (low turnover) in being there.
 - I matter.
 - Service providers understand the “lived experience” and respect the “lived experience” of parents who have a child with a disability.
- Goal V: Clear accountability for achieving service results for lowans that support individuals to live, learn, work, and recreate in communities of their choice.
 - Youths' Perspective
 - At the agency, I am engaged and they demonstrate cultural competence in service delivery.
 - They don't give up on me.
 - I receive regular communication in writing of my progress and goals.
 - I can find information about the system.
 - I can be maintained in the home.
 - I am on grade level, attending school, and working towards graduation.
 - I am not picking up criminal charges.

- I graduate with the skills I need.
- When I am referred to another specialist or PCP, I don't have to tell my story over again.
- My ability to have friends and engage with the community is important.
- I have peer supports when I need them.
- If something in the plan isn't working, there is a commitment to developing a new plan.
- Parents' Perspective
 - I know that the system providers are looking at data, and constantly proving themselves.
 - I have a seat at the table before decisions are made.
 - "Nothing about me without me."
 - I have peer supports when I need them.
 - There is a system for measuring customer satisfaction that matters.

These are starting points for outcomes to strive for in the Redesign. The pressing needs are regarding out of state placements, and potential out of state placements, and identify points of re-entry to services in Iowa.

Points of Coordination

In advance of this meeting, workgroup members were asked to think about the structures/entities needed to coordinate and develop comprehensive service plans for the multi-system kids that will be returning from out of State. If all of the out-of-State youth returned tomorrow what entities are best equipped to coordinate the effort? For discussion purposes, potential points of coordination for re-entry were identified as Child Protective Services, CPCs or soon to be developed Regional entities, existing comprehensive youth treatment agencies and entities currently providing care coordination services.

Before each potential coordinating entity was discussed, a number of key factors were discussed.

- Who is most trusted now? What entity is most neutral?
- What happens to the kids that go out of state, and what is the protocol for returning? This is a fragmented process.
- What is the out of state placement's involvement with the family and their process for discharge? Service connections need to be made prior to the youth returning to home.
- We need to know how to build supports around the youth and the family.
- Families need to have service connections and be able to work across systems without barriers.
- Staff needs to be dedicated and reimbursed for their efforts to assist in reconnections to the service system.
- Use Family Navigators to identify all the systems that need to be involved and get the systems involved prior to the discharge. Services need to be ready/in place before discharge.
- Do we need to think about reserving slots?

- Families need continuity before, during and after a child's out of home placement.
- Transition and discharge planning needs to begin at admission to an out of state placement.
- The "youth never stops being a member of his/her home community," and the community should be seeing the changes the youth is making. This creates a more welcoming back to the home community.
- The community needs to demonstrate readiness to change too. "Community needs to change and make modifications—not the kid."
- If we don't bring the child back into a safe environment, we will have recidivism.
- Out of home placement is a "treatment option" not an "end game solution."
- We need to approach this from two ends: bringing kids currently out of state home AND serving those in the pipeline for placement. Otherwise they will just fill the empty beds.

Pros and cons of potential "Coordinating Entities."

1. A part of/co-located with multi-county Regional Entities

- Pros
 - Focus on developing Systems of Care across the lifespan.
 - Can concentrate skill sets better in regional areas versus by separate counties.
 - Helps other community partners to understand the structure across the state.
 - The needs/funding/volunteers/supports of families and folks can better understand from a single point of coordination.
 - Consistency in approach that you can capture for youth — decision making about services.
 - Same array of core services.
 - Easier for community funders to understand the array of services, general populations and their needs.
- Cons
 - CPC experience is with adults and not youth.
 - Will youth get the same priority status as adults?
 - Waters down the specialty care of youth.
 - Doesn't respect the specialties of providers.

2. Child Protection Services

- Pros
 - Know the youth service system.
 - Able to balance a family's needs along with provide help.
 - Some experience in creating balanced plans for the youth/family.
- Cons
 - Not particularly skilled in Mental Health or Developmental Disabilities.
 - Seen as a crisis agency versus a long term care agency.
 - Stigmatizing to access services through Child Welfare.

- Parents feel they lose control.
- Let's the local community off the hook as it relates to ownership.

3. Private Providers

- Pros
 - Experts on provision of a youth's treatment.
 - Experience working across Child Welfare systems — community engagement, volunteer networks, boards.
 - Reduces the duplication of "leads"—roles/plans/communication.
 - Opportunity to do coaching and service delivery.
 - Develop capitated funding systems.
 - Infrastructure exists with licensed professional staff; could deploy more quickly with enhancements. Integrated with education systems.
 - Could capitate at provider level.
- Cons
 - Some may not be experts in "systems."
 - How do I know who to go to?
 - Lack of availability across the state.
 - Conflict of interest if serving as care coordinator and helping family find treatment/placement provider.
 - Building it within existing infrastructure can be a disadvantage and making a new system would be better.
 - Active staffing level.

Existing Systems of Care include wraparound services, family navigators, the use of natural supports, and community connections. Does it make sense to use a System of Care for the out of state youth? The main points of discussion included:

- Do we develop a small-scale System of Care to bring kids back? Or Do we develop a System of Care for all multi-system kids?
- Can we compare the cohort group of 134 kids who are out of state with those currently in placement in Iowa? In other words, are there already examples of us effectively serving similar youth?
- Community transformation will make all the difference for the youth and the family.

4. Systems of Care Entities

- Pros
 - Understand the elements for success in a System of Care.
 - Demonstrated success in two geographic areas.
 - Efficacy has been well-researched nationally.
 - Are keeping kids out of placement.
 - More likely to recognize the need for community transformation.
 - Designed to be flexible and to be evolving.
 - Adept at constantly changing, measuring, and evolving.
 - Are serving children in foster placements currently and those at higher risk.

- Cons
 - In limited geographic areas at this time.
 - The service seems harder to do and less well defined—it doesn't follow existing formulas.
 - Large scale collaboratives are hard to sustain.
 - Adherence to the model is difficult.
 - Need to adapt the model to fit the particular community.

There are 13 Title V agencies across Iowa that all provide service coordination and adhere to Systems of Care principles.

Kevin Martone from TAC will facilitate the next Children's Workgroup session in Kappy Madenwald's absence.

NEXT STEPS:

Information requested for next meeting:

- Information on study done at the Iowa Training Schools re: mental health treatment for youth.
- Data on Iowa clients with ID and Autism Spectrum Disorder diagnosis in an OOS placement.

September 13, 2011 Agenda items:

- Multi-system care coordination needs.
- Core services that will ensure successful return to least restrictive home/community setting.
 - ID
 - MH
- Envisioned timeframes:
 - for engagement/planning for return; and
 - for initial intensive period post return.
- Education — will ask Julie Curry about presenting at the next meeting.

MEETING SUMMARY:

- Reviewed the best practice information for transition age youth.
- Reviewed data of Iowa children in an out of state placement and the cost of care in an out of state placement.
- Overview of two Systems of Care in Iowa and how beneficial/successful they have been in keeping youth in their home communities.
- Goals of the Olmstead Act and how youth and their parent(s) might describe outcomes of a successful reform.²
- Discussed points of re-entry into Iowa services and the pros and cons associated with each point of re-entry.

² Though parents are represented on the Children's Workgroup, the goal of this exercise was not to speak "for" parents and children. The resulting "working list" of outcomes is neither complete nor final. It simply serves as a reminder to the workgroup of the kind of outcomes that matter to children and families.

PUBLIC COMMENT:

Comment: A parent shared how her child was recently placed out of state, and would have benefitted from a family navigator guiding her as she worked through the system. There is a DHS SW assigned to her child's case, but the DHS SW does not return telephone calls and it is not enough; she needs another person to assist her. When she brings her values and choices to the table, all she hears is 'this is our program and we don't do it that way.' She has 'tangential knowledge' about Asperger's, and shared other treatment needs her child may have. This is not her son's first out of home placement, and more information about outpatient mental health services, such as Partial Hospitalization Program would have been helpful for her son upon his discharge from PMIC.

She further expressed concern that the missing people at the workgroup were judges and CINA lawyers. Children and families come into the court systems, but the court systems do not recognize who they are.

She attended a conference on Autism recently, and found it helpful to connect with other families who have a special needs child. She highlighted the need for more community support, and a Special Needs PTO at the school. She is petrified not having confident skills on service deliverables and cited the need for more parent education from the treatment center. She is looking for cutting edge strategies, and for the school to have more brain based strategies. She is confused on how services are reimbursed, and strongly suggested a management information system, with visuals and graphics like GPS, to light up where a youth has been in the service process.

Response: You gave a good illustration of the need for wraparound services. Thank you for sharing your story.

Comment: Systems of Care has a slogan, 'nothing about me without me.' There is a need for the youth to be involved in the process. ELEVATE is good example of youth getting involved in their service planning. There is also a need to bring a more broad- base of parental voice into the workgroup to make better decisions.

Response: Joanna Schroder gave information about advocacy group meetings that will be held in four Iowa regions with the first meeting being on 09/16/11. Advocate groups will also get a survey monkey email as a way to provide input into the regional meetings. She reminded members of the audience to sign the attendance sheet and list an email address so that they can receive communication about upcoming meetings and documents.

Next meeting is September 13, 2011, 10:00 am – 3:15 pm at the West Des Moines Public Library, Community Room.

For more information:

Handouts and meeting information for each workgroup will be made available at:
<http://www.dhs.state.ia.us/Partners/MHDSRedesign.html>

Website information will be updated regularly and meeting agendas, minutes, and handouts for the six redesign workgroups will be posted there.